



Improving the Lives of All Affected by Autism

Oregon

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Ms. Vikki Wachino
Deputy Administrator and Director
Center for Medicaid and CHIP Services
US Department of Health and Human Services
7500 Security Boulevard
Rockville, MD 21244

Dear Ms. Wachino,

The Autism Society of Oregon (ASO)) respectfully submits the following comments in response to the state of Oregon's request to extend its Section 1115 Demonstration Waiver. We are writing to request that the extension of the waiver for the Oregon Health Plan NOT be approved until two critical issues are fixed: (1) the EPSDT Waiver; and (2) consumer representation on the Health Evidence Review Commission (HERC).

I am the Executive Director of the Autism Society of Oregon, the largest autism group in Oregon and the only one that operates state-wide. We represent everyone affected by autism in Oregon, including individuals on the autism spectrum and their families, across the autism spectrum and throughout the life span. Our mission is to empower these individuals to improve the quality of their lives through resources, education, advocacy and support. Over 9,000 children are identified as having an autism spectrum disorder in Oregon. Their families access ASO as a resource throughout Oregon.

I am also the mother of two children on the autism spectrum who are covered by Oregon Health Plan (OHP). Their Coordinated Care Organization (CCO) is Health Share in Multnomah county. Over their lifetimes, they have accessed autism therapies including speech therapy, occupational therapy and Applied Behavior Analysis (ABA) therapy.

EPSDT WAIVER:

The EPSDT benefit was created by Congress to ensure that children enrolled in Medicaid receive "the right care at the right time in the right setting" by requiring coverage of "all medically necessary diagnostic and treatment services ... regardless of whether or not such services are otherwise covered under the state Medicaid plan for adults ages 21 and older."

The Oregon Health Plan includes a waiver from this Congressional requirement, permitting Oregon to restrict coverage to only those services on the "prioritized list." While the original intent may have been to focus coverage on best practice treatment, in practice it has been used to ration care and cut costs by withholding medically necessary care from needy children.

CMS should require Oregon to ensure that its most vulnerable children receive the medically necessary care that Congress intended, without rationing, by making it clear that Oregon must fully comply with EPSDT. The federal government should not sanction the refusal of Oregon's CCOs to provide mental healthcare to children so that the CCOs can save money.

CONSUMER REPRESENTATION ON THE HEALTH EVIDENCE REVIEW COMMISSION:

The Health Evidence Review Commission (HERC) develops the prioritized list of healthcare services. According to the waiver application, HERC is supposed to include "two health consumers."

What has actually happened is that qualified "health consumer" applicants for the HERC were rejected and appointed to these seats were (1) a Board member of a Care Coordinating Organization (CCO) and (2) a health care industry consultant. As a consequence, there are NO *bona fide* "health consumers" on HERC.

Consumer representation is critical. HERC regularly discusses ways to mitigate the financial impact of its decisions about the prioritized list on CCOs *without genuine consumer representation*. There is very little consideration of the impact on health consumers.

The HERC membership clause in Oregon's section 1115(a) waiver should be clarified to specify that the "Health Consumers" must actually be *bona fide* consumer representatives who are either (a) Medicaid recipients, or the parents or guardians of Medicaid recipients; or (b) representatives of non-profit advocacy organizations representing the needs of Medicaid consumers. Industry representatives should not be considered consumer representatives.

Thank you for the opportunity to submit these comments. If you have any questions, please feel free to contact me by email at info@AutismSocietyOregon.org, or by phone at 503-636-1676.

Very truly yours,

A handwritten signature in blue ink that reads "Tobi Rates". The signature is stylized with a large, sweeping "T" and a cursive "Rates".

Tobi Rates
Executive Director